

NATIONAL INSTITUTES OF HEALTH
FISCAL YEAR 2005
PLAN FOR HIV-RELATED RESEARCH

XII: INFORMATION
DISSEMINATION

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
OFFICE OF AIDS RESEARCH

AREA OF EMPHASIS:

Information Dissemination

SCIENTIFIC ISSUES

Effective and efficient information dissemination and exchange are important tools in the effort to control and end the AIDS epidemic. The NIH has responsibility for disseminating information to support research, treatment, and prevention related to HIV and AIDS. Progress in these areas depends on the transfer of information to researchers, health care and service providers, HIV-infected individuals and their families, policymakers, and the public. These audiences have varying needs for information that is critical in the fight against HIV/AIDS. The changing demographics of the epidemic provide challenges to disseminating HIV research results to communities at risk in the United States, including women and minorities, as well as those at risk in developing countries. An additional challenge is providing information in formats that are useful to both health care providers and patients. The flow of information among researchers, health care providers, and the affected communities represents new opportunities to rapidly translate research into practice and to shape future research directions.

A Guide to NIH HIV/AIDS Information Services is updated annually and made available in both printed and electronic form through the National Library of Medicine (NLM) AIDS Web site (<http://aids.nlm.nih.gov>). This guide provides a comprehensive listing of NIH-supported information services that assist care and service providers, patients, and the public.

TREATMENT GUIDELINES

Access to clinical care guidelines, standards of care, and results of state-of-the-art meetings is critical for physicians and patients. Treatment guidelines for the use of new and complex antiretroviral regimens are continually updated. The guidelines are available in print form and on the Internet Web site of AIDSinfo (<http://AIDSinfo.nih.gov>). Titles available include the following:

- *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents*
- *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection*
- *Public Health Service Task Force Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1 Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV-1 Transmission in the United States*
- *Updated U.S. Public Health Service Guidelines for the Management of Occupational Exposures to HBV, HCV, and HIV and Recommendations for Postexposure Prophylaxis*
- *Management of Possible Sexual, Injecting-Drug-Use, or Other Non-occupational Exposure to HIV, Including Considerations Related to Antiretroviral Therapy*
- *Guidelines for the Prevention of Opportunistic Infection in Persons Infected with HIV*
- *Updated Guidelines for the Use of Rifabutin or Rifampin for the Treatment and Prevention of Tuberculosis Among HIV-Infected Patients Taking Protease Inhibitors or Nonnucleoside Reverse Transcriptase Inhibitors*
- *Prevention and Treatment of Tuberculosis Among Patients Infected with HIV: Principles of Therapy and Revised Recommendations*

ELECTRONIC INFORMATION RESOURCES

Computerized databases and other types of electronic resources are a vital component of NIH AIDS information dissemination, allowing global access to information concerning basic research, clinical trials availability and results, standards of care, and other information of interest to HIV-infected individuals, their care providers, and their advocates. Examples of these critical resources follow.

NLM Databases

Internet: <http://pubmed.gov>

MEDLINE/PubMed is available free of charge to users worldwide. The AIDS subset of this database includes citations (with abstracts when available) to AIDS-related journal articles and newsletters. Abstracts from significant AIDS-related meetings and conferences, notably the International AIDS Conferences, are included in the new Gateway (<http://gateway.nlm.nih.gov>), which also provides access to other NLM information resources. International, national, and State organizations involved in AIDS are found in DIRLINE (<http://sis.nlm.nih.gov/Dir/DirMain.html>).

AIDSinfo

Internet: <http://AIDSinfo.nih.gov/>

Phone: 1-800-HIV-0440 (1-800-448-0440)

Fax: 1-301-519-6616

Outside U.S.: 1-301-519-0459

TTY: 1-888-480-3739

Monday to Friday, 12:00 p.m. to 5:00 p.m. Eastern Time

Spanish-speaking health information specialists are available.

E-mail: ContactUs@AIDSinfo.nih.gov

In December 2002, the HIV/AIDS Clinical Trials Information Service (ACTIS) and its sister service, the HIV/AIDS Treatment Information Service (ATIS), were merged into AIDSinfo. The AIDSinfo project provides all of the services that were previously available from ACTIS and ATIS, as well as quick and easy access to wide-ranging Federal resources on HIV/AIDS clinical research, HIV treatment and prevention, and medical practice guidelines for health care providers and consumers. AIDSinfo includes databases that provide information about new and ongoing clinical trials that evaluate experimental drug treatments and candidate vaccines, including descriptions of clinical trials and the agents studied in those trials. The Web site also provides HIV vaccine information, supporting materials such as fact sheets, and links to published trial results and to other databases. The AIDSinfo Web site is user-friendly and easy to navigate. The site's many features include:

- Federally approved information on HIV/AIDS treatment and prevention guidelines

- Comprehensive database of Government- and industry-sponsored HIV/AIDS clinical trials
- Information about approved and experimental HIV/AIDS drugs and vaccines
- Education and Resource Center, offering links and other downloadable resources

AIDSinfo is sponsored by the National Institutes of Health: Office of AIDS Research, National Institute of Allergy and Infectious Diseases, and National Library of Medicine; Centers for Disease Control and Prevention; Health Resources and Services Administration; and Centers for Medicare and Medicaid Services.

NIH Web Pages

The NIH continues to expand and improve its use of the Internet as an important medium for HIV/AIDS information dissemination efforts. NIH home pages, such as those for the NIH overall (<http://www.nih.gov>), the Office of AIDS Research (OAR) (<http://www.nih.gov/od/oar>), and all of the NIH Institutes and Centers (ICs) and Office of the Director (OD) offices, provide extensive HIV/AIDS research and programmatic information for the public, patients, health care providers, scientific investigators, press, and policymakers. Fact sheets, brochures, and news releases are also available. In particular, the National Institute of Allergy and Infectious Diseases (NIAID) Division of AIDS Web page (<http://www.niaid.nih.gov/daids/>) provides extensive and comprehensive AIDS information. NLM also has created a Web site specifically for HIV/AIDS-related information (<http://aids.nlm.nih.gov>). This site serves as an entry point to many of the HIV/AIDS-related resources available from the NIH and serves as a guide to selected resources worldwide. Another NLM site is Medlineplus, which includes AIDS pages for consumers (<http://www.nlm.nih.gov/medlineplus/aids.html>).

REPORTS OF MEETINGS, CONFERENCES, AND WORKSHOPS

The NIH sponsors and supports a myriad of meetings, conferences, and workshops each year that bring together scientific experts to discuss critical scientific issues and develop recommendations or guidelines. The NIH makes the reports of these meetings available to the public in both written and electronic form through the various NIH Web sites.

**COMMUNITY
OUTREACH
PROGRAMS**

Providing accurate and up-to-date HIV/AIDS prevention and treatment information to communities at risk, including women and minorities, is a critical challenge. The NIH has a number of ongoing projects to address HIV/AIDS in minority and underserved communities.

Since FY 1994, the NIH, through NLM, has made annual awards of up to \$40,000 to enable community-based organizations and public and health science libraries to design their own programs for improving access to AIDS information for targeted groups, including people living with HIV/AIDS, their caregivers, communities at risk, and the general public. These awards support activities such as purchasing equipment and telecommunications services, implementing Internet access, training in the use of sophisticated information tools, and developing language- and culture-specific materials.

Training in the use of electronic HIV/AIDS resources, including the use of online databases, is included in NIH information dissemination programs. Curriculum-based AIDS information programs and modules are made available nationwide, including through the Historically Black Colleges and Universities (HBCUs) and other groups of minority health professionals, such as the National Association for Equal Opportunity in Higher Education (NAFEO). Training is also carried out in conjunction with the U.S. Department of Health and Human Services (DHHS) Office of Minority Health Resource Center.

Regional Technology Transfer Program

OAR sponsors a series of regional information dissemination programs to bring current research findings to community health professionals, particularly in minority communities, and to populations with the least access to information. This is accomplished through regional workshops, exhibit displays, and collaborative programs with other agencies and organizations.

Regional Workshops

OAR also sponsors regional workshops targeted to Hispanic, Native American, Asian and Pacific Islanders, and African American communities. Events also have focused on issues relating to women, children, and injecting drug users. These 2-day events provide a forum for the presentation of research information. To ensure that the meetings are culturally appropriate and effective, they are planned in collaboration with scientists, researchers, community leaders, people living with HIV/AIDS, and care providers in the community.

Conferences

OAR, in collaboration with the Health Resources and Services Administration, provides support to the National Minority AIDS Council (NMAC) for a series of conferences held in locations with the highest rates of HIV infection among minority populations in the United States. The purpose of these conferences is to help community-based organizations and leaders in case management and treatment meet the wide range of challenges in HIV treatment and adherence in communities of color. These conferences are unique opportunities for health care workers to receive critical research updates that contribute to the quality of care and life for infected individuals. This program has been in operation for 6 years.

Exhibit Displays

OAR has developed two exhibits that are displayed at events in the United States and abroad. These exhibits offer insight into the HIV/AIDS research programs at the NIH.

The NIH AIDS Research Program Exhibit provides information on the HIV/AIDS research programs conducted and supported by the National Institutes of Health. The exhibit provides publications, fact sheets, treatment guidelines, information about NIH Web sites, including AIDSinfo, and order forms for information from the Institutes and Centers. The exhibit provides this critical information about the NIH AIDS research program to scientists, health care workers, social workers, community-based workers, patients, and the public at domestic and international scientific and community-oriented events.

The Children's Art Exhibit was designed by OAR in collaboration with the Pediatric HIV Working Group of the National Cancer Institute (NCI). To help individuals better understand the challenges and triumphs of living with HIV and AIDS, this exhibit presents artwork created by children, adolescents, and young adults participating in the clinical trials of the Pediatric HIV Working Group of the NCI. The pictures in the exhibit are created by these young people, and in some cases their noninfected siblings, who are using this art to give form to their psychological experiences and tell the story of their journey of living with HIV and AIDS.

International Technology Transfer Program

Information and outreach programs for Latin America and the Caribbean have been a key priority for OAR for many years. OAR has collaborated for the past 12 years with the Office of Continuing Medical Education at

the University of Puerto Rico and the AIDS Education and Training Centers of Puerto Rico on a series of meetings on key AIDS research topics. In 2000, in response to congressional appropriations language encouraging attention to AIDS in the U.S. Virgin Islands, OAR worked with Representative Donna Christian-Christensen to host a meeting on the island of St. Thomas. Plenary sessions were broadcast by satellite to other Caribbean islands, including the Bahamas, Jamaica, Trinidad and Tobago, and Barbados. Participants on each island viewed the morning plenary sessions and then conducted afternoon workshops to address topics of local interest. Most of the plenary and workshop sessions were captured on videotape and made available for broader viewing and posted on the OAR Web site.

Efforts are now underway in the Caribbean to plan another event targeted to the Spanish-, French-, and Dutch-speaking countries of the Caribbean in March 2004 in Santo Domingo, Dominican Republic.

The program has been expanded to address critical needs in Africa. In 1999, a meeting on *Education and Training for Community-Based Health Care Workers from Kenya, Tanzania, and Uganda* was held in Nairobi, Kenya, and a second meeting was held in Mombasa, Kenya.

Collaboration with National Community-based Organizations

OAR collaborates with a number of organizations addressing HIV/AIDS issues in racial and ethnic minority communities. OAR supports approximately 10 regional conferences each year focusing on treatment issues. These meetings are held in locations with the statistically highest HIV/AIDS rates in the United States.

- OAR provides scholarship funds for attendance at the U.S. Conference on AIDS, sponsored by the NMAC.
- OAR has developed AIDS Information Kiosks that have been placed in strategic locations for access by at-risk populations, including in community college settings, at the University of Puerto Rico, through grassroots organizations working with youth, and with faith-based organizations. These computer kiosks allow directed searching through the Internet to learn more about HIV and AIDS. The home page and links created for this site direct the user through information on topics they query in English or Spanish.

- For the past several years, OAR has sponsored a scholarship program to provide computers to community-based organizations. These organizations use them for their own research and knowledge and also make them available to their clients. The computer is available to each successful awardee for 1 year and includes the necessary software, Internet service, telephone access, and training to develop an internal capability to enhance AIDS programs and services through this access. At the end of the year, the organizations have the option of purchasing the hardware and software licenses at reduced prices and assuming the other costs.
- Meet the Expert sessions are presentations by experts on specific topics that are broadcast over the Internet, and then followed by a live chat. The entire package of activities is captured on tape and is available for viewing on the OAR Web site.
- In partnership with World Internet Resources for Education and Development, OAR provides resources to establish computer stations and medical information libraries in Community Health Information centers in Kenya. Training is provided to local individuals, and a local infrastructure is developed to allow communities to help each other access vital health care information and develop networks of care and support.

SCIENTIFIC OBJECTIVES AND STRATEGIES

OBJECTIVE - A:

Support the effective dissemination, communication, and utilization of HIV/AIDS information to all constituent communities of the NIH, domestically and internationally.

STRATEGIES:

- Rapidly disseminate new research findings with information on their potential implications for prevention, care, and treatment of HIV-infected individuals, using existing and innovative methods.
- Facilitate the development of HIV prevention and treatment guidelines based on the latest clinical research findings.
- Utilize computer and other information dissemination technology (including the Internet) to disseminate up-to-date HIV/AIDS information; information about HIV therapeutic, vaccine, and prevention trials; and information about HIV training programs.
- Expand access to and education about current state-of-the-art treatment and patient management guidelines, including information on clinical trials, using multiple technologies such as online access and voice access (AIDSinfo).
- Improve current techniques and develop and evaluate new techniques for the two-way communication of information to scientific and lay audiences, particularly to hard-to-reach populations, including information about clinical trials.
- Improve outreach and support access to HIV/AIDS information resources (including computers) by community groups, health care providers, and community-based HIV/AIDS service organizations, including those serving minority communities.
- Work with community-based organizations (CBOs) to develop and promote effective methods of information dissemination in target populations.
- Develop and disseminate educational information to enhance understanding of HIV and basic and clinical research processes by health care providers, community-based HIV/AIDS service organizations, social service organizations, policymakers, and persons with HIV/AIDS.

- Develop and disseminate information resources about HIV vaccine clinical trials and the importance of potential HIV vaccines.
- Evaluate the effectiveness of communication efforts by appropriate means, including obtaining feedback from target audience members through such methods as usability testing of paper and computer interfaces (*see* www.usability.gov) and information dissemination intermediaries, such as journalists and health educators.
- Promote wide dissemination of the annual *NIH Plan for HIV-Related Research* and other HIV-related reports as they become available.
- Promote and enhance the exchange of scientific information and communication between public and private research enterprises, such as enhancing communication with the pharmaceutical industry concerning research on the development of therapeutics, vaccines, and microbicides, and working with industrial scientists to make information concerning basic science and HIV protein structures available to the general scientific community.
- Communicate and exchange information internationally on topics such as prevention and treatment, patient management guidelines, and research results that improve the care of HIV-infected individuals, including those in developing countries.
- Support the exchange of basic and applied research information at community, regional, national, and international conferences and workshops.
- Support the cross-collaborations of HIV/AIDS information providers to develop more integrated and comprehensive information dissemination approaches.
- Provide online access to presentation materials, including full text of abstracts and other information (e.g., slides, graphics, plenary presentations) from scientific meetings.
- Collect, archive, and promote use of existing data from NIH-supported basic and applied research for secondary data analysis, including rapid development of public use data sets that can be used for secondary data analysis in NIH-supported studies, especially baseline survey and HIV/STD (sexually transmitted disease) incidence data.

- Widely disseminate information concerning specimen repositories, including existing repositories, specimens available, and relevant information concerning cohorts, contact information, and the process for obtaining access to samples.

OBJECTIVE - B:

Support research to identify existing gaps in communication approaches, identify and evaluate existing strategies, and develop and test new and innovative communication strategies that will improve access to and use of state-of-the-art HIV information by all relevant target audiences, domestically and internationally.

STRATEGIES:

- Assess the information needs and resources used by various audiences, including biomedical and behavioral research communities, health care providers, service providers, persons living with HIV and their advocates, at-risk populations, scientific and lay media, and the general public.
- Identify obstacles to information dissemination and develop, test, and evaluate possible ways to overcome these obstacles.
- Develop, test, and evaluate innovative strategies for effectively reaching specific audiences (e.g., minority communities, adolescents, drug users, other hard-to-reach populations, and health care providers) with relevant HIV information.
- Investigate how and under what circumstances different communication and dissemination strategies influence the adoption of scientifically based HIV behavior-change interventions and clinical practices in specific audiences.
- Promote use of new technologies and evaluate their effectiveness for disseminating basic and clinical research findings.
- Work to reduce communication gaps between academic researchers and treatment providers so that research results are more effectively disseminated to providers and that research agendas reflect the needs of practicing clinicians.

OBJECTIVE - C:

Develop, implement, and evaluate methods of coordination and collaboration on HIV/AIDS communications activities among NIH ICs and with other Federal and non-Federal groups.

STRATEGIES:

- Build and enhance partnerships among CBOs and basic, clinical, and behavioral researchers to encourage exchange of information and experience.
- Promote and foster information dissemination regarding research and programmatic efforts across the ICs, among U.S. Government agencies, and with international partners.
- Promote collaboration among all ICs in providing information about their HIV/AIDS clinical trials to AIDSinfo and ClinicalTrials.gov.
- Expand the development of HIV/AIDS resources on the Internet to facilitate national and international research collaboration and data sharing.
- Continue collaborations with the Joint United Nations Programme on HIV/AIDS, the Pan American Health Organization, and other international AIDS agencies or societies on information/communications efforts, including information about international clinical trials.
- Collaborate with public and health sciences libraries, health care providers, AIDS education and training centers, and community-based HIV/AIDS service organizations to facilitate access to needed information.
- Expand collaboration to include academic, medical, and other communities, as appropriate, in the dissemination of NIH HIV-related reports.

APPENDIX A:

NIH Institutes and Centers

NIH INSTITUTES AND CENTERS

NCI	National Cancer Institute
NEI	National Eye Institute
NHLBI	National Heart, Lung, and Blood Institute
NHGRI	National Human Genome Research Institute
NIA	National Institute on Aging
NIAAA	National Institute on Alcohol Abuse and Alcoholism
NIAID	National Institute of Allergy and Infectious Diseases
NIAMS	National Institute of Arthritis and Musculoskeletal and Skin Diseases
NIBIB	National Institute of Biomedical Imaging and Bioengineering
NICHD	National Institute of Child Health and Human Development
NIDCD	National Institute on Deafness and Other Communication Disorders
NIDCR	National Institute of Dental and Craniofacial Research
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
NINDS	National Institute of Neurological Disorders and Stroke
NIDA	National Institute on Drug Abuse
NIEHS	National Institute of Environmental Health Sciences
NIGMS	National Institute of General Medical Sciences
NIMH	National Institute of Mental Health
NINR	National Institute of Nursing Research
NLM	National Library of Medicine
CC	Warren Grant Magnuson Clinical Center
CIT	Center for Information Technology
NCCAM	National Center for Complementary and Alternative Medicine
NCRR	National Center for Research Resources
FIC	John E. Fogarty International Center
CSR	Center for Scientific Review
NCMHD	National Center on Minority Health and Health Disparities

APPENDIX B:

List of Acronyms

LIST OF ACRONYMS

ACSR	AIDS and Cancer Specimen Resource, NCI
ACTIS	AIDS Clinical Trials Information Service
AIDS	acquired immunodeficiency syndrome
AITRP	AIDS International Training and Research Program, FIC
ART	antiretroviral therapy
ARV	antiretroviral
ATI	analytic treatment interruption
ATIS	AIDS Treatment Information Service
AVEG	AIDS Vaccine Evaluation Group
BSL	biosafety level
B/START	Behavioral Science Track Award for Rapid Transition
CAB	community advisory board
CAPS	Center for AIDS Prevention Studies (University of California, San Francisco)
CBO	community-based organization
CDC	Centers for Disease Control and Prevention
CIPRA	Comprehensive International Programs for Research on AIDS
CMV	cytomegalovirus
CNS	central nervous system
CSF	cerebrospinal fluid
CTL	cytotoxic T lymphocyte
DC	dendritic cell
DHHS	Department of Health and Human Services
EBV	Epstein-Barr virus
FDA	Food and Drug Administration
GBV-C	GB virus (hepatitis G)
GCP	Good Clinical Practices
GCRC	General Clinical Research Center
GFATM	Global Fund for AIDS, Tuberculosis, and Malaria

GI	gastrointestinal
GLP/GMP	good laboratory practice/good manufacturing practice
GRIP	Global Health Research Initiative Program, FIC
HAART	highly active antiretroviral therapy
HBCU	Historically Black Colleges and Universities
HBV	hepatitis B virus
HCV	hepatitis C virus
HHV	human herpesvirus
HIV	human immunodeficiency virus
HPV	human papillomavirus
HSV	herpes simplex virus
HVTN	HIV Vaccine Trials Network
IC	Institute and Center
ICC	invasive cervical cancer
IDU	injecting drug user
IND	investigational new drug
IRB	institutional review board
IUD	intrauterine device
JCV	JC virus
KS	Kaposi's sarcoma
KSHV	Kaposi's sarcoma herpesvirus
LRP	Loan Repayment Program, NIH
MAb	monoclonal antibody
MAC	<i>Mycobacterium avium</i> complex
MDR-TB	multidrug-resistant tuberculosis
MHC	major histocompatibility complex
MSM	men who have sex with men
MTCT	mother-to-child transmission
NAFEO	National Association for Equal Opportunity in Higher Education
NGO	nongovernment organization

NHL	non-Hodgkin's lymphoma
NHP	nonhuman primate
NIH	National Institutes of Health
NK	natural killer (cell)
NMAC	National Minority AIDS Council
NNTC	National NeuroAIDS Tissue Consortium, NIMH/NIDA/NINDS
NRTIs	nucleoside reverse transcriptase inhibitors
OAR	Office of AIDS Research, NIH
OARAC	Office of AIDS Research Advisory Council
OD	Office of the Director, NIH
OI	opportunistic infection
PACTG	Pediatric AIDS Clinical Trials Group
PCP	<i>Pneumocystis carinii</i> pneumonia
PML	progressive multifocal leukoencephalopathy
RCT	randomized clinical trial, randomized controlled trial
RNA	ribonucleic acid
RPRC	Regional Primate Research Center
SCID	severe combined immunodeficiency
SHIV	chimeric simian/human immunodeficiency virus
SIT	scheduled intermittent therapy
SIV	simian immunodeficiency virus
SPF	specific pathogen-free
STD	sexually transmitted disease
STI	structured treatment interruption; sexually transmitted infection
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	U.S. Agency for International Development
VRC	Vaccine Research Center
WHO	World Health Organization
WIHS	Women's Interagency HIV Study
WRAIR	Walter Reed Army Institute of Research

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Additional copies are available on the OAR Web site
www.nih.gov/od/oar